



## Pakistan Journal of Neurological Sciences (PJNS)

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Volume 15 | Issue 4

Article 9

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12-2020

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#### Recommended Citation

Khan, Qurat ul ain (2020) "Assessment of Dementia Caregiver Burden in Karachi, Pakistan using 10/66 Protocol," *Pakistan Journal of Neurological Sciences (PJNS)*: Vol. 15 : Iss. 4 , Article 9.

Available at: <https://ecommons.aku.edu/pjns/vol15/iss4/9>

# ASSESSMENT OF DEMENTIA CAREGIVER BURDEN IN KARACHI, PAKISTAN USING 10/66 PROTOCOL

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Date of submission: July 12, 2020 Date of revision: September 28, 2020 Date of acceptance: September 29, 2020

## ABSTRACT

**INTRODUCTION:** Care arrangements and caregiver burden of people with dementia (PWD) are different in low and middle income countries (LMICs) than in developed countries. This is the first study in Pakistan assessing caregiver burden using the 10/66 protocol.

**METHOD:** PWD were recruited from outpatient clinics and from the community in Karachi and were diagnosed according to DSM-IV TR. Three scales were used: 1. Zarit Burden Interview (ZBI) to assess caregiver burden. 2. Caregiver Activity Survey (CAS) to assess activities that the caregiver engaged in the last 24 hours to care for PWD and 3. General Health Questionnaire- 12 (GHQ 12) to assess caregiver emotional distress. The scales were translated, back translated, and tested for conceptual validity in Urdu. The data was entered using EPIDATA and was assessed using SPSS version 22.0. Ethical approval was obtained from institutional review board of Aga Khan University, Karachi.

**RESULTS:** Mean Zarit Burden Interview score was 11.5 and had significant positive correlation with the caregiver's level of education ( $p=0.04$ ) and age ( $p=0.008$ ) and negative correlation with the mini mental status exam (MMSE) score. An average of 40 minutes per day were spent by the caregivers with PWD in communicating. The mean General Health Questionnaire score was 2.3 with a standard deviation of 3.1.

**CONCLUSION:** Caregiver training and education methods should be devised especially for older caregivers, those with low level of education, and those taking care of people with moderate stages of dementia. Caregiver support strategies should be devised to manage caregiver distress.

**KEY WORDS:** Burden, caregiver, dementia, general health questionnaire 12, Pakistan, zarit burden interview

## INTRODUCTION:

Dementia is a progressive, neurodegenerative condition that is estimated to affect 75 million people worldwide by 2030 with majority (63%) living in low and middle income countries (LMICs). <sup>(1)</sup> Dementia affects different domains of cognition including short term memory, language, executive functions, personality, and visuospatial skills. This causes compromise of instrumental activities of living such as shopping, travelling, driving, managing money, making decisions etc. At later stages people with dementia (PWD) may even have compromised daily activities of living such as eating, bathing, toileting, walking etc. PWD may suffer from confusion, disorientation, neuropsychiatric and behavioral symptoms such as wandering, agitation, difficult night time behaviors, appetite changes,

delusions, hallucinations etc. Because of the disabling nature of the condition, PWD need increasing care and supervision especially as the condition progresses. Carers of PWD face more anxiety, depression, and physical problems than non dementia caregivers and the situation may be even more challenging in LMICs due to different care arrangements, and lack of institutionalized care, formal caregivers, and community resources. <sup>(2)</sup>

Pakistan is a LMIC in South East Asia with a population of over 200 million people and is currently the sixth most populous country of the world. <sup>(3)</sup> 6% of the total population is elderly people and this number is expected to double by 2050. <sup>(4)</sup> Some dementia studies have been done in Pakistan including caregiver studies,

(5,6) however 10/66 protocol has not been used. This is the first caregiver study done in Pakistan using the 10/66 protocol. We aim to study the dementia caregiver burden in community dwelling PWD in Karachi, Pakistan.

### **MATERIALS AND METHODS:**

The study was completed using the 10/66 protocol. The results from this study including validation and care assessment are reported elsewhere. In this study we will report results from using Zarit Burden Interview (ZBI), Caregiver Activity Survey (CAS), and General Health Questionnaire- 12 (GHQ 12).

ZBI scale was developed by Zarit et al <sup>(7)</sup> and has cross cultural use <sup>(8)</sup>. It is used to assess care burden in caregivers of PWD. It is a 22 item scale and each item is rated on a 4 point Likert scale ranging from “never” (0) to “nearly always” (4). Questions include items to assess different aspects of caregiver burden such as social life, meeting household responsibilities, financial, physical and emotional burden. Examples of some questions from the scale are: “Do you feel that your relative asks for more help than he/she needs?”, “Do you feel that because of the time you spend with your relative you do not have enough time for yourself?”, “Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?”. The raw scores from the scale can be analyzed as numeric variable and can also be categorized into four groups: 0-20: little or no caregiver burden, 21-40: Mild caregiver burden, 41-60: Moderate caregiver burden, 61-88: Severe burden.

CAS is a part of 10/66 DRG protocol and assessed different types of activities that the caregiver engaged in, in the last 24 hours in taking care of the PWD. It includes 6 items: 1. communicating with the person 2. Using transport. 3. Dressing 4. Eating 5. Looking after one’s appearance and 6. Supervising the person. The 7th item is open ended. The activities are measured in time spent every day by the caregiver in minutes and/or hours.

The GHQ was developed by Goldberg in 1978 <sup>(9)</sup> and measures the mental health status especially distress in the form of emotional disorders. GHQ 12 has 12 items and it was scored in binary fashion with two least symptomatic answers scored as 0 and two most symptomatic answers scored as 1 (0-0-1-1). The scores can range from 0- 12 with higher scores indicating higher levels of mental distress. The caseness threshold is 3 for GHQ 12. <sup>(10)</sup>The items include questions such as: “Have you recently been

able to concentrate on whatever you are doing?”, “Have you lost much sleep over worry?”, “Have you recently felt that you are playing a useful part in things?”, “Have you recently felt capable of making decisions about things?”

The scales used in the study were translated, back translated, and tested for conceptual validity in Urdu, which is the national language of Pakistan. The scale was pilot tested in 10 people.

Two data collectors were hired one of whom was an MBBS doctor and the other was an MPhil psychologist. Both of them were trained to use the 10/66 protocol by the PI.

PWD were recruited from i. Psychiatry, Neurology, Neuropsychiatry and sub specialty clinics at the Aga Khan University Hospital, which is a private, tertiary care hospital in Karachi. ii. Communities in the city including Police Line community which is a residential society of retired police officers in Karachi, RLCC (Rana Liaquat Ali Craftsmen Colony) which is a community of semi skilled women workers, and gated communities of Ismaili population in Karachi that includes Shia Muslims with extremely organized structure. PWD recruited from nursing homes are excluded from this study as we intend to study the burden in caregivers of community dwelling PWD. Dementia diagnosis was made according to the diagnostic and statistical manual of mental disorders (DSM-IV TR) and CDR (clinician dementia rating) scale was used for rating severity of dementia.

The procedures used in this study are in compliance with the Helsinki Declaration of 1975, as revised in 2008. This study was approved by the institutional review board (IRB) of Aga Khan University (3868-Psy-REC 15).

Written informed consent was obtained from PWD and their caregivers. A copy of consent form and information sheet were provided to PWD and caregivers both in English and Urdu and study was also explained to them verbally. In those PWD who were not able to understand the study fully, consent was taken from the family members, however this was the case in only a few PWD as those with severe dementia were not included in the study. Participants were not paid for taking part in the study however an amount of Rs 500 was paid as travel expense for those who had to travel to AKU to participate and they requested reimbursement.

The funding for this study was provided by the AKU, University Research Council (URC) Grant 144003PSY. Data for the study was collected from September 2016 until August 2017.

The original data was entered using EPIDATA and was re-entered to check for errors. The data obtained was analyzed on SPSS for Windows 22.0 software. Number, percentage, mean and standard deviation were used during analysis. Pearson correlation was used for analyzing correlation between continuous variables. Odds ratios were calculated with 95% confidence intervals. Multiple Linear Regression analysis was used with the GHQ-12 score as the dependent variable and entering total MMSE score, total ZBI score, and total Aga Khan University Anxiety and Depression Scale (AKUADS) score as independent predictors using stepwise method.

## RESULTS:

The total number of people included in the study was 119. Mean age of caregiver was 43 years and majority were females. Mean ZBI score was 11.5 with minimum of 0 and maximum of 58 and standard deviation of 10.7. The relationship of ZBI score with caregiver and PWD characteristics is reported in Table 1.

Characteristic	Number	Mean (SD) ZBI score	p-value	Correlation
<b>Patient</b>				
CDR Score			0.01	0.46
MMSE score	>21	7.2 (8.6)	0.01	-0.39
	>15	18.3 (1.6)		
	<= 15	12.2 (3.8)		
<b>Caregiver</b>				
Age			0.008	0.24
Gender	Male	10.5 (8.9)	0.46	
	Female	12 (11.6)		
Marital Status	Single	11.5 (9.9)	0.9	
	Married	11.4 (11)		
	Divorced/	10		
	Separated	21 (11.3)		
	Widowed	2		
Education	No formal	7(6.9)	0.04	
	Minimal	10 (14.7 (7.7)		
	Primary	18 (9.7 (6.5)		
	Secondary	21 (13.9 (14.6)		
	college or higher	63 (11.3 (10.9)		
PWD	Depressed	11.9 (11.7)	0.6	
	Non- Depressed	11 (9.8)		
Relation	Spouse	12 (9.3)	0.99	
	Son/ Daughter	47 (10.8 (10.6)		
	Daughter/son in law	17 (12.7 (15.3)		
	Sibling	2 (16.5 (3.5)		
	Other relative	2 (8(11.3)		
	Friend	3 (10.6 (8)		
	Neighbor	1 (9)		
	Others	9 (10.5 (11.7)		

Table 1: Relationship of PWD and caregiver characteristics with ZBI score

SD: Standard deviation; ZBI: Zarit burden interview; CDR: Clinician dementia rating, MMSE: Mini mental state exam; PWD: People with dementia

The results of CAS reporting time spent/day by the caregiver with PWD are mentioned in Table 2.

Task	Time/ minutes/day
Communication	40
Arranging transportation	17
Helping to dress up	8
Helping to eat	12
Looking after appearance	16
Supervision	5

Table2: Average time spent per day with people with dementia (PWD)

The mean GHQ score was 2.3 with a standard deviation of 3.1. 64 % (76) had GHQ score < 3. 36% (43) had GHQ score ≥3. See Table 3

Model	Beta coefficient	P value
MMSE score	-0.263	0.02
ZBI score	0.133	0.16
AKUADS score	0.208	0.02
CDR total score	0.17	0.12
Caregiver age group	0.06	0.41

Table 3: Stepwise multiple regression analysis

R squared: 0.33, Adjusted R squared: 0.27

Model Statistics: Multiple Linear Regression analysis with the GHQ-12 (General Health Questionnaire – 12) score as the dependent variable and entering total MMSE (Mini Mental State Examination) score, total Zarit burden interview (ZBI) score, and Total Aga Khan University Anxiety and Depression Scale (AKUADS) score, Total Clinician Dementia Rating (CDR) score, and caregivers age group as independent predictors using stepwise method.

## DISCUSSION:

Mean ZBI score in our population was 11.5 which falls in the no or little caregiver burden range. We observed that quite a few family members and caregivers did not report caregiving as a burden due to religious and social beliefs of the society as has been noted in some other studies. <sup>(11)</sup> Serving the elders is considered obligatory in Pakistani society and people attach feelings of guilt and inadequacy with not being able to fulfill the needs of elderly family members with dementia. ZBI score showed a significant negative correlation with MMSE score, burden being highest for MMSE scores between 15- 21 (moderate dementia). This fits with the idea that increasing severity of dementia increases caregiver burden of caregivers. <sup>(12)</sup> Similar finding is reflected by the statistically significant positive relationship between CDR score and ZBI score, CDR score also being reflective of severity of dementia. Hence MMSE <sup>(13)</sup> and CDR scores may be used as useful indicators in predicting caregiver burden and for designing appropriate caregiver strategies. The ZBI score did not significantly differ by gender of the caregiver in our study. Some studies have reported higher caregiver burden in female caregivers. <sup>(14)</sup> There was a statistically significant positive correlation between increasing caregiver age and ZBI score. This has also been reported in the literature <sup>(15)</sup>. This is an important finding as older spouses who are caregivers of PWD may find

responsibilities of caregiving more burdensome; this may compromise caregivers' health and subsequently health of PWD and may require special attention when dealing with older couples with dementia. The burden did not show any significant difference between those caring for PWD who were depressed and those who were not depressed. Regarding relationship with the caregiver, the mean ZBI score was highest when sibling was the caregiver however it was statistically insignificant. Relationship of caregiver to PWD has been found to impact caregiving and caregiver burden in other studies as well <sup>(16)</sup>. For marital status, the mean ZBI score was highest for widowed caregivers however the relationship of marital status with burden was statistically insignificant. The ZBI score was also statistically significantly correlated with the level of education of caregivers with highest burden among caregivers with minimal education. Low educational attainment has been associated with increasing burden in caregivers in the literature <sup>(17)</sup>.

When looking at the time spent by the caregivers in different activities with PWD, most of the time was spent in communication. This may be a particularly difficult area for untrained family caregivers of PWD especially when their communication and language skills are compromised due to decline in cognitive abilities. Caregiver education and training programs should be devised especially focusing on strategies to improve communication which may improve quality of life of PWD and may reduce caregiver burden. Difficulties in communication was followed by the time required in arranging transportation for PWD. In Pakistan this may be a problem especially for middle and lower middle class people who rely on public means for transportation such as buses. The buses are not in very good condition, are often very crowded, and do not have designated space for people with disabilities or wheel chairs. There are also often separate sections in the buses for males and females and travelling of a male PWD and female caregiver or vice versa may be particularly difficult in buses. Roads are in a bad state and are often congested. Taxis and cabs may not be affordable for everyone. This makes travelling and transportation difficult for PWD and caregivers.

For GHQ administered to caregivers, one third of total caregivers scored 3 or above showing caseness level and mental distress. Thus one in three caregivers was suffering from mental distress due to caregiving responsibilities. MMSE score had a statistically significant negative correlation with the GHQ score indicating that lower MMSE scores and increased severity of dementia may increase demands of

caregiving and thus mental distress of the caregiver. Lower MMSE score has been associated with higher GHQ score in caregivers in other studies as well <sup>(18)</sup>. There was a positive correlation between ZBI score and GHQ score but was not statistically significant. There was a statistically significant positive correlation between AKUADS score and GHQ score which signifies the fact that depressed PWD may have higher caregiving demands which may take a toll on the caregiver. This correlation has also been reported in other studies <sup>(19)</sup>. Correlation was positive but statistically insignificant for CDR score and caregivers' age group. The R square value for the GHQ variable is 0.33 showing relationship of the independent variables in variance of GHQ scores. These findings have important implications when dealing with patients and families who have dementia and in devising the right strategies for management.

**Limitations:** This study was conducted in Karachi; its generalizability to rural areas of Pakistan and other geographical locations may be limited.

**Conclusion:** One in three caregivers suffered from mental distress hence there is a need to devise strategies to manage PWD, especially focusing on improving communication and transportation and also to come up with programs which provide financial, emotional and psychological support to caregivers.

#### CONFLICTS OF INTEREST: NONE

**Acknowledgment:** The study was funded by the AKU, University Research Council (URC) Grant 144003PSY. The funding source had no involvement in study design, in the collection, analysis and interpretation of data, in the writing of the report, and in the decision to submit the article for publication.

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Conflict of interest: Author declares no conflict of interest.

Funding disclosure: Nil

Author's contribution:

**Qurat ul ain Khan;** concept, data collection, data analysis, manuscript writing, manuscript review